

Social participation and health-related quality of life in adolescents with chronic musculoskeletal pain or chronic fatigue

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Chapter 7

Valorisation

Introduction

This valorisation paragraph represents the societal value of the results of this thesis. Valorisation is transferring scientific knowledge to, for example healthcare organisations, by making knowledge available and suitable for economic and social exploitation. It is the translation of knowledge into products, services, processes or new business.

The results presented in this thesis are published in peer-reviewed journals. Several oral and poster presentations have been provided to share the results with health care professionals and to spread the clinical implications. Also articles are posted on social media and websites to share the outcomes with patients and their parents.

In this chapter, the relevance for patients and their families, therapists, medical specialists and health insurance companies, will be presented, followed by examples of innovative activities.

Target groups

The results of this thesis are relevant for different groups of people, especially for adolescent patients with chronic musculoskeletal pain or chronic fatigue. In the Netherlands, some of them who have to cope with severe disability, are treated in a rehabilitation setting. Therefore, the relevance of the results is also applicable for rehabilitation therapists and physicians in rehabilitation medicine treating adolescents with chronic pain or fatigue. The results are also of interest for general practitioners, school physicians, other health care professionals and health insurance companies.

Relevance for adolescents with chronic musculoskeletal pain or chronic fatigue

Patients and their parents: you are not alone! Your complaints are quite common and might persist over time. As you know your complaints have a considerable impact on your daily and leisure activities and school functioning. Some of you will be referred for inpatient rehabilitation treatment. Twelve to 17 years ago these patients were mostly girls around the age of 16 and the complaints existed on average for three years.

What can be expected of this inpatient rehabilitation treatment? According a rather strict definition almost half (49.6%) of these adolescents had a successful treatment. On the long-term (10 years later) the total population that received rehabilitation is quite active and participating, with a reasonable quality of life. A large proportion

of the participants still reported to have complaints, although these were on average of a lower intensity level than at the start of treatment.

In follow-up healthcare attention should be paid to future work ability, because of the present higher level of work absenteeism compared to healthy peers. Also, we advise to offer those adolescents experiencing difficulties in the transition to adulthood a 'refresher course' in order to improve their coping in this new phase of life (e.g. identified based on screening by a questionnaire or consultation when necessary).

Relevance for rehabilitation therapists and physicians

The message for rehabilitation therapists and physicians: Start or keep on continuously monitoring to improve diagnostics and treatment based on assessment. Collecting data can help to gain insight into influencing factors and working elements of treatment and helps to adjust treatment.

In clinical practice the parent form of the Child Health Questionnaire can be used to measure changes in quality of life. It is important to know that boys, adolescents with a higher level of pain/fatigue, and patients with a higher passive coping seem to benefit more from an inpatient treatment. Therefore, it seems relevant to more specifically address passive coping during treatment.

On the long term, adults having received clinical rehabilitation during adolescence for chronic pain or fatigue, have more work absenteeism than their healthy peers. It is therefore recommended to pay extra attention to future work abilities during treatment in adolescence. Adolescents should be invited for follow-up care in the phase of transition into adulthood. A 'refresher course' when they are going to live on their own or when they start working.

Relevance for other medical specialists

To other medical specialists and health care professionals, specifically general practitioners, paediatricians, and school physicians, the message is: When the adolescent patient is older, has chronic fatigue, has higher pain/fatigue scores or a more passive coping style, it is possible that social participation and health-related quality of life are at stake. Earlier referral or referral anyway to rehabilitation for these adolescents should be considered.

In case an adolescent reports lots of pain or fatigue to a health care professional, some specific attention is needed for further exploring a possible underlying mechanism. This might be a key to the possible long-term restrictions in health-related quality of life, which should be prevented.

Relevance for health insurance companies

Given the scale, complexity and impact of pain and fatigue problems, it is preferred to arrange care for adolescents with fatigue and pain in healthcare networks. Based on a stepped care approach (from a bio-psychosocial perspective) with providers in primary to third care included. The Pain Alliance in the Netherlands (PAIN) can have a facilitating role in this transition of care. This way of arranging care for adolescents with chronic pain will fit the proposed health care service in the Dutch standard of care for chronic pain.

Implementation, innovative and future activities

It is recommended to further design the National database for adolescents with chronic pain or fatigue, according to the PedIMMPACT criteria and in accordance to the Dutch Dataset Painrehabilitation for adults. We advise to use a minimal dataset in every patient admitted to rehabilitation programs. As a consequence, it is possible to evaluate the treatment on the level of the individual, and also on an aggregated level. In this National database at least the following data should be collected: demographic characteristics, the level of complaints (pain as well as fatigue), personal goals, activity and participation level, health-related quality of life and psychosocial factors, like catastrophizing (for adolescent and parent), coping and system factors, e.g. protective behaviour.

It is also recommended to involve health care professionals working with adolescents with chronic pain and fatigue in formulating research questions out of clinical practice.

In this way, we can hopefully build a solid bridge between research and clinical practice in order to further improve care for adolescents with chronic pain and fatigue.

